The Bioethics Online Service - An Implementation of a Bioethics Database and Information Resource

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ABSTRACT

Ethical analysis is crucial to decision making in biomedicine and health care, necessitating rapid access to diffusely disseminated sources of information pertinent to bioethics. We developed the Bioethics Online Service to provide this access and to provide a forum for discussion of bioethical issues. The service, originally designed as a local resource, was expanded to allow Internet access and now enjoys widespread extramural use. We have logged over 8,000 users from our campus, around the state, the nation, and 42 other countries. This model has shown promise in utility and ease of access, and is being used as the template for other informatics developments on our campus and beyond.

PURPOSE

The next several years will bring significant changes in American health care and the way it is provided to persons of different ages, gender, socioeconomic status, and geographic locations. Ethical analysis is crucial to the evolution of these changes; and access to scientific, economic, legal, philosophical, and health policy information is crucial to ethical analysis.

Institutional ethics committees, ethics consultants, primary care physicians, health care institutional administrators, health care legal counsel, and students in the health care field need to obtain information about bioethical issues quickly and accurately. Additionally, there is an increasing interest on the part of the public to learn about and participate in the discussion of issues in bioethics. At present this is not an easy task.

Part of the problem is that information about bioethics is disseminated diffusely. Court decisions, state statutes, journal articles, newspaper accounts, professional society and association position statements, federal and state government agency decisions, and published hospital ethics committee decisions add to the information base in bioethics each day. No one source can be relied upon for up-to-date, pertinent bioethics information — be it the medical library of a medical school, law school, or philosophy department, or through a legal case update service, administrative journals, or news service.

Another part of the problem is that the need for information is often time-critical. Ethics committees, ethics consultants, physicians, nurses, attorneys, and ethicists need accurate, recent information urgently. In fact, the Wisconsin Ethics Committee Network (WECN), a statewide consortium of over 180 hospital and long-term care facility ethics committees, sponsored by the Medical College of Wisconsin (MCW), found itself in need a time-efficient and appropriate means for its members to communicate about its activities and resources.

For busy individuals seeking ethics information, the task of synthesizing these disparate materials is formidable. One needs the expertise of the clinician, the ethicist, and the lawyer to pull together the pertinent information, to explain how the information applies to specific cases, and to show where the information fits into the larger picture. It was exactly this type of synthesis delivered through a centralized resource that WECN members and other bioethics experts wanted.

METHODS

In response to these needs, we developed the **Bioethics Online Service**, which was inaugurated in June, 1993 at MCW. This service consists of these features:

- The **Bioethics Database** is an update service which provides MCW-produced abstracts of pertinent bioethics journal articles, legislative actions and court decisions. It also provides an intermittent commentary about current bioethics issues. Online information is updated every week and the database is searchable by key words. Over 550 abstracts are available at this time.

- The **Bioethics Bulletin Online** publishes articles of interest from the Medical College of Wisconsin's Bioethics Bulletin.

- The **Bioethics Resources** section serves as an archive and clearinghouse for ethics and ethics committee policies and other resources.

- The **Bioethics Reference Texts Online** area electronically publishes (with publishers' and authors' permission) helpful reference texts and position statements on bioethics topics. This section currently contains over 50 entires from about ten texts.

- The **Bioethics Discussion Forum** facilitates discussion of current bioethics cases and topics.

- The **Bioethics Center News and Announcements** section posts current bioethics news and announcements from the Medical College of Wisconsin and other academic and professional sources.

- The **Wisconsin Ethics Committee Network (WECN) News and Announcements** section posts current bioethics news and announcements from the Wisconsin Ethics Committee Network, a consortium of ethics committees from acute and long term care facilities in Wisconsin. The Bioethics Online Service acts as a core communications vehicle for WECN members.

- The **Directory of U.S. and Canadian Bioethics Networks and Centers** directs users to other resources in bioethics.

- Through **Electronic Mail**, users can communicate personally with other users of the service, Bioethics Center faculty, and other individuals worldwide through Internet.

Technical Implementation

The Medical College's Office of Research, Technology, and Information has successfully partnered with the Bioethics Center to implement the Bioethics Online Service through MCW's Medical Information Network (MIN). This internal network is tied to Wiscnet for state-wide communications, Internet for national and international access, and services such as America Online for convenient connection to the Internet. This configuration offers points of access for faculty, staff, students, other professionals and lay public. Thus, the Bioethics Online Service can be accessed by anyone with a computer, a communications program, and a modem from almost any location.

In the course of developing this service, several internal and external database and information management programs were evaluated. Gopher emerged as the system of choice to facilitate access from multiple routes, provide a highly structured (menu-based) method for information organization and retrieval, and implementation costs were minimal using existing computer and staff resources. This standard Internet tool is a text-based data system, searchable, easy to implement and maintain. Gopher will allow search and retrieval of text, files, telnet resources, sounds and graphics. Gopher runs under UNIX on a VAX at MCW which is connected to the Internet through the Wiscnet network. Usually, Gopher requires that the user have "client" software. However, MCW's telnet and dial-in connection system provides a Gopher client as part of a menu choice to connect to the Bioethics Online Service.

In analyzing the content to be housed in the Bioethics Online Service, the subject matter was discovered to be very diverse. The most common resources consist of tables of contents from pertinent journals, journal articles, advance sheets from court decisions, garnering newspaper stories, and other resources, (e.g. books sent for review). Our own set of key words (N=1450) were identified and developed by our abstracter with input from MCW Bioethics faculty based upon trends in the literature. These key words facilitate the Gopher search as the current implementation of Gopher does not support multiple-word phrase searches nor boolean logic in a search strategy. Also, a structured keyword system will help us to prepare for the possibility of eventually evolving toward a true database program supporting all of the searching and reporting functions this type of service requires.

The selection of Internet for our service was based upon the increasing ease of connectivity and access to the Internet among academic, business, and individual users. Internet is the Transmission Control Protocol/Internet Protocol (TCP/IP) based world wide network system connecting more than 2,000 other networks including wide-area networks, midlevel and regional networks, and campus and organization local networks in the U.S., Canada, Mexico, Japan, Europe, New Zealand, and Australia, with estimates of more than 1 million computers connected, and 15 million users. Wiscnet, our link to the Internet, is a state-wide high-speed logical network that connects academic institutions in Wisconsin.

Because of the demand for an interactive case discussion service through which subscribers from the bioethics, legal, medical, and philosophical communities could exchange ideas and information about specific or hypothetical cases, we sought to provide online interactive functions including public posting and archiving of information. At present, the technical implementation of the Gopher interface does not support these functions without linking traditional bulletin board software (BBS) to the Bioethics Online Service.

The few available UNIX versions of bulletin board software that were reviewed were felt not to have an appropriate interface for the Bioethics Online Service. Other (PC and Macintosh) BBS software packages were considered, but these required additional separate systems. All of these systems require significant input and organization from system operators (sysops) or discussion group moderators, which would add significant burdens to our limited human and financial resources.

Therefore, we turned to an automatic mailing list processor, Listproc, to address these needs. This list processor supports automatic enrollment of users, distribution of cases and subsequent commentary, and links to existing Gopher-based services. This link allows the list processor to be mirrored to a local campus bioethics news group and the main Gopher-based Bioethics Online Service. Thus, Gopher serves as a permanent, read only archive sorted in reverse chronological order, while the mirrored list processor and news group allow for on-going discussion among participants using either service.

RESULTS

Initially, the Bioethics Online Service was meant to be a communication and information resource for WECN members (N= est. 500). The Bioethics Online Service was demonstrated at regional WECN conferences and ethics committee meetings. However, though initial interest was enthusiastic, few WECN members participated. We found that the majority of WECN members were not computer literate and did not know the fundamentals of telecommunication. Secondly, those who knew about telecommunication had a difficult time learning to navigate their local route of access to connect to MCW through the Internet. Different access sites had different procedures and variable costs for gaining connection. To address these problems we initiated a series of outreach and training seminars. Unfortunately, the staff time was a significant factor. To address these limits on staff resources, we attempted to enlist librarians and information specialists located within or proximate to a user to demonstrate the service.

Interestingly, when we analyzed the numbers of users by where the connection originated, we found that our extramural use far exceeded our intramural use, i.e. the Internet was our most common route of access, and the vast majority of connections were not from WECN members. Nonetheless, on our campus use has fluctuated around a mean of approximately 175 log-ons per month and our off-campus average is 476 per month.

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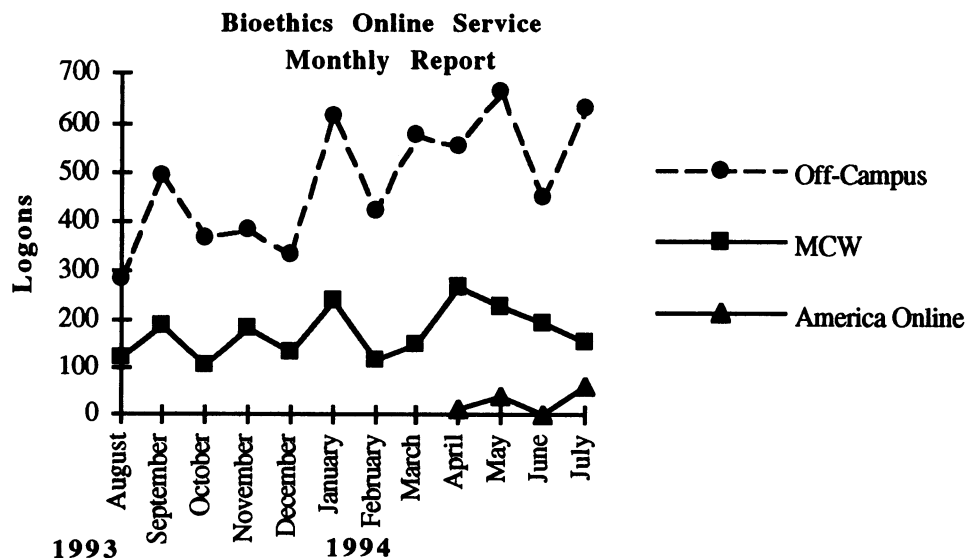
Additionally, the Bioethics Online Service has been used in education at MCW. Our Masters students in Bioethics have used the Service in conjunction with course work for research and professional development, and medical students have used it as an introduction to various topics in bioethics. A clear advantage of the Service format identified by these users is its 24 hours per-day accessibility from any location.

The Bioethics Online service has attracted national attention. America Online (AOL), the nationwide information service with over 700,000 subscribers, has chosen the Bioethics Online Service as a "featured" database for their Internet users because of exemplary presentation of material with value and interest to their users and because it is, in their words, a reliable and well-maintained resource.

Future Plans

The Bioethics Online Service plans to enhance its role in the dissemination of bioethics information. In coming months, we plan to establish these new features:

1) an ethics committee fact file to allow rapid access to information specifically designed to aid ethics committees, including an ethics committee case directory, which will collect information about and analyze ethics committees' case consultations;

2) a bioethics educational programming clearinghouse, for the dissemination of information and ideas about bioethics teaching and research;

3) comprehensive retrospective searches of Medline and other sources such as legal databases to make sure that no significant information items have been neglected.

4) a biweekly current headline bioethics news update service.

We also plan to establish these new links:

1) an affiliation with a national bioethics organization as its official bulletin board,

2) a link to the national freenet system with access for Omnifest, the local freenet.

CONCLUSION

Through the Bioethics Online Service, the Bioethics Center at the Medical College of Wisconsin will help local, national, and international audiences of health care professionals, students, institutions, and the lay public confront the ethical challenges posed by continued scientific advances.

As a result of our endeavors, other educational institutions have expressed plans to create online services based on the Bioethics Online Service. We applaud these efforts and look forward to the development of similar services worldwide.

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